

HOUSE BILL REPORT

ESSB 5111

As Reported By House Committee On:

Health Care

Title: An act relating to health insurance discrimination on the basis of genetic information.

Brief Description: Prohibiting health insurance discrimination on the basis of genetic information.

Sponsors: Senate Committee on Health & Long-Term Care (originally sponsored by Senators Franklin, Winsley, Thibaudeau, Wojahn, McAuliffe, Fraser, Prentice, Rasmussen, Kline, Brown, Eide, Bauer, Costa, Jacobsen, Spanel, Goings, Loveland, Gardner, Fairley, B. Sheldon and Kohl-Welles).

Brief History:

Committee Activity:

Health Care: 3/25/99, 4/1/99 [DPA].

Brief Summary of Engrossed Substitute Bill
(As Amended by House Committee)

- Establishes protections against inappropriate use of genetic information.

HOUSE COMMITTEE ON HEALTH CARE

Majority Report: Do pass as amended. Signed by 10 members: Representatives Cody, Democratic Co-Chair; Parlette, Republican Co-Chair; Pflug, Republican Vice Chair; Schual-Berke, Democratic Vice Chair; Alexander; Boldt; Campbell; Conway; Edmonds and Ruderman.

Minority Report: Do not pass. Signed by 1 member: Representative Mulliken.

Staff: Bill Hagens (786-7131).

Background:

There is a global effort underway to map the entire human genetic structure by the year 2005. As the research has progressed, scientists have linked over 4000 diseases and disorders to genetic origins. Genetic links have been discovered for such illnesses as cystic fibrosis, hemophilia, Huntington's disease, sickle-cell anemia, and various forms of cancer.

The benefits of this research are available to humans through genetic tests which can tell an individual what their own genetic makeup is. Genetic tests are conducted by analyzing body or blood tissue to determine an individual's genetic composition. An individual who is aware of his or her genetic predisposition toward a particular illness may, in some cases, be able to postpone or lessen the effects of the disease through medicines, monitoring, or lifestyle changes. Genetic data can also assist couples in making informed family planning choices by telling them what conditions their children may face.

There is concern that health carriers may use the genetic information from these tests to remove individuals with a predisposition for high cost diseases from their policies. Congress passed the Health Insurance Portability and Accountability Act in 1996 which prohibits a group health plan from denying enrollment based on an individual's genetic information if the person has not yet been diagnosed with symptoms of the disease. In addition, 33 states have passed legislation further limiting insurance carriers' use of genetic test results in denying applications, adjusting premiums, terminating, or not renewing coverage, or taking other adverse action.

Summary of Amended Bill:

A health carrier (health maintenance organization, health care service contractor, or disability insurer) may not deny or cancel health coverage, or vary premiums, terms, or conditions for health plan coverage on the basis of genetic information or because of a request for genetic services as defined in the act. Genetic information may not be disclosed without the consent of the individual. Genetic information may be used for approved research projects or by health care carriers for disease prevention screening. There is an exemption for the Department of Health's newborn screening activities.

Amended Bill Compared to Engrossed Substitute Bill: Definitions and procedures for access by researchers are clarified.

Appropriation: None.

Fiscal Note: Available.

Effective Date of Amended Bill: Ninety days after adjournment of session in which bill is passed.

Testimony For: Computerization allows for the fast exchange of large amounts of data and genetic information is personal and needs to be protected from misuse. Genetic tests are useful, but individuals are not having them performed because of the fear that the information will be used against them by insurance companies.

Testimony Against: Banning the use of genetic information will inhibit the treatment of patients with genetic diseases. This bill is not necessary in a guarantee issue state such as Washington. The state cannot regulate the self-insured market; therefore, this bill would fail to cover many citizens.

Testified: (in support) Senator Franklin, prime sponsor; David Allen, American Cancer Society; Kris Coppin, individual; and Jerry Sheehan, American Civil Liberties Union.

(opposed) Ken Bertrand, Group Health.

(needs amendment) Cliff Webster, Pharmaceutical Research and Manufacturers of America.